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ABSTRACT

This collection of 21 suggested outcome measures for early childhood intervention services is designed to assist families in evaluating the quality of early intervention services they receive. The measures apply to all types of service and support program models for children with various developmental delays and/or disabilities and their families. The measures are appropriate for home-based, center-based, and community-based service delivery models. The outcome measures evaluate eight areas, including family involvement in choosing services; family involvement in goal determination; the rights of children and families; respect for families; health and safety of the children; relationships; security; and family satisfaction with services. For each of the measures, the values underlying the desired outcome are explained and suggested questions are provided that are indicative of the quality of the program or service. (CR)

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A Consumer's Guide to Outcomes in Early Childhood Intervention

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PREFACE

This guide is a companion piece to *Outcome Measures for Early Childhood Intervention Services*, also published by The Accreditation Council. The *Outcome Measures for Early Childhood Intervention Services* includes an overview of the values foundation for early intervention. It also includes descriptions and principles for each of the 21 Outcomes for Families and Children, along with information gathering questions and decision making guidelines for use in evaluating the quality of services and supports. Organizational Outcomes for early childhood intervention services are also included in this publication.

The Accreditation Council provides a variety of training, technical assistance and consultation options for early intervention service organizations.

For information about publications and other services, please contact:

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Introduction

Families as Consumers

Families naturally want what's best for their children. They want their children to grow up happy and healthy, experiencing a good life. Of course, families of children with developmental delays or disabilities have those same hopes for their children. But often, their children have special needs—needs that sometimes require assistance and supports from sources outside the family. When it comes to these services and supports—these early intervention services—families want what's best for their children and their entire family.

Families who receive early intervention services and supports are consumers and are truly customers of the service system. As customers, families should expect to receive the best services possible and should be included in the evaluation of services. Early intervention services should continually ask families about their satisfaction with services. With this in mind, early intervention service providers should actively seek feedback and input from families so services can be improved. They should continually strive to meet family needs and expectations.

Family-Centered Services

The time when families first connect with early intervention services can be confusing and overwhelming. Families often do not know what to expect from services and supports. They realize that their children have special needs and seek assistance in providing support to help boost their development. Quite often, though, families do not realize the early intervention services are aimed at lending support to the entire family. Certainly, your family wants services that enhance your child's development, but quality early intervention services can do more than that. Since the family environment is where your child grows and develops, services should be provided in ways that support your whole family.

During your first contacts with the early intervention system you should be asked about concerns you have about your child's development. You should also be asked if there are any supports you might need as a family. For example, you might need information about general parenting concerns, economic assistance, medical care, managing your

child's behavior, medical insurance, child care, etc. You should be asked if there are additional supports you might need as a parent. This type of discussion should happen on an ongoing basis as your family and child receive services.

Once you have identified your needs and concerns, early intervention service staff should help you address both child development and family issues. Sometimes your service providers may help you find assistance from other sources in your community. In many instances, there are sources of supports that families do not know about. Early intervention programs can link you to those resources.

Families can be confident knowing that early intervention service providers have considerable expertise that can be helpful in many ways. But they should know that early intervention is a partnership between families and professionals. Early intervention professionals should ask about family concerns, listen carefully and respond in meaningful ways. Families should be welcomed as team members and partners. Without full partnership between families and professionals, services will have limited positive effects.

Quality of Early Intervention Services

This Consumer's Guide is designed to provide a tool to assist families in evaluating the quality of early intervention services they receive. It is meant to help families be more informed consumers or customers of early intervention services and supports. Families sometimes find it difficult to judge the quality of their services because they do not know what their expectations should be. The issues and questions raised in this guide are intended to bring these expectations into focus for families.

In the following pages are 21 Outcomes for Families and Children found in the *Outcome Measures for Early Childhood Intervention Services*. These Outcome Measures were developed based on information provided by families of children with developmental delays or disabilities. Families themselves defined the outcomes of services they valued most. Although these outcomes are meant to help define quality services to children with developmental concerns and their families, they are the types of outcomes families want for all of their children.

Outcome Measures for Early Childhood Intervention Services apply to all types of service and support programs and to families of children with various developmental delays and/or disabilities. They can be used in a variety of settings such as home-based, center-based and community-based services.

In the following pages, the Consumer's Guide highlights the Outcomes for Families and Children, including the values statements that guide each outcome. Questions about how your service provider addresses issues related to each outcome are also included under each outcome. If the answer to many of the questions is "no," that indicates that many outcomes may not be present for your child and family. That might also indicate that the service provider needs to completely change or modify the ways they provide services to your family to better support your desired outcomes.

Upon discussion with other families that have used the Consumer's Guide you might find that they share concerns about the quality of available early intervention services. If that is the case, parents may choose to join together to voice their concerns and make a positive change in the service system. Connections with organized parent/consumer groups might also lead to enhancements in system quality.

Families are reminded that most early intervention service providers are very concerned about the quality of the services they provide. Many see families as the key participants in their plans for improving service quality. Your service provider may be unaware of the *Outcome Measures for Early Childhood Intervention Services* or this Consumer's Guide. You may wish to show this book to them as a resource for beginning a dialogue about improving the quality of services. Your family and your early intervention service provider can then work cooperatively toward making these improvements. You may even find ways to include other families in this process since their input is important too.

OUTCOME MEASURES FOR FAMILIES AND CHILDREN

CHOICE

1. Families are informed.
2. Families choose services and supports.

GOALS

3. Families choose their goals.
4. Families choose child developmental goals.
5. Families attain their goals.
6. Children attain developmental milestones.

RIGHTS

7. Families exercise their rights.
8. Children are free from abuse and neglect.

RESPECT

9. Families are respected.
10. Families decide when to share personal information.

HEALTH AND SAFETY

11. Children have the best possible health.
12. Children are safe.

RELATIONSHIPS

13. Families remain together.
14. Children spend time in natural environments.
15. Children develop relationships.
16. Families remain connected to natural supports.
17. Families are a part of their communities.

SECURITY

18. Families have economic resources.
19. Families experience continuity and security.

SATISFACTION

20. Families are satisfied with their services.
21. Families are satisfied with their life situations.

1. Families are informed

Values

A family's need for information is met in a timely, comprehensive manner.

Assessment information provides answers to a family's questions about the child's developmental situation.

Questions about Quality:	Yes	No
Did your child receive the assessments/evaluations you wanted?	❑	❑
Did you understand the purpose and/or need for each assessment?	❑	❑
Did anyone explain your role in the assessment process?	❑	❑
Was assessment information communicated in understandable terms?	❑	❑
Were all of your questions answered after assessments were conducted?	❑	❑
Did you receive information about other resources/services in your community if you needed it?	❑	❑
Do staff ask you about your ongoing needs for information?	❑	❑
Were assessments conducted within a period of time that enabled your family to make decisions and initiate action?	❑	❑
Are all of your needs for information met?	❑	❑

2. Families choose services and supports

Values

Families make decisions about the manner in which services are delivered.

Families access services and supports quickly and easily.

Early intervention services are driven by family choice rather than the structure, schedule or staffing of the service providers.

Questions about Quality:	YES	NO
Did you select the services you receive?	❑	❑
Did you determine the schedule for your services—appointment times, scheduling sessions, etc.?	❑	❑
Did you determine how much of each service you would receive?	❑	❑
Did you determine where your child and family would receive services (at your home, at a center or preschool or somewhere else in your community)?	❑	❑
Have staff asked you if there are any other additional services you might like?	❑	❑
Were you able to easily access needed services and supports?	❑	❑

3. FAMILIES CHOOSE THEIR GOALS

VALUES

Early intervention providers assist families in identifying goals that are important to them.

Services assist families in identifying goals.

QUESTIONS ABOUT QUALITY:	YES	NO
Have staff asked you if there is anything you hope your family learns or achieves while you receive early intervention services?	❑	❑
Do staff ask you if there is anything you would like to change about your family life?	❑	❑
If so, have they asked you what assistance you might need to make these things happen?	❑	❑
If you identified family goals, have they been supported by the coordination of services and supports?	❑	❑

4. FAMILIES CHOOSE CHILD DEVELOPMENTAL GOALS

VALUES

Families receive support to identify important developmental goals for their child.

Goal development is a collaborative process between families and early intervention practitioners.

Identified goals are described in measurable outcome statements that are fully understood by all.

QUESTIONS ABOUT QUALITY:	YES	NO
Have staff asked you if there are specific skills you hope your child learns during the next year or so?	❑	❑
Have they asked you what assistance your child might need to learn these things?	❑	❑
Do staff listen to your concerns about your child's development?	❑	❑
Are the goals in the plan your goals for your child?	❑	❑
Did staff ask you if there were any additional people you would like to have had as participants in the planning process when developmental goals for your child were identified?	❑	❑
Are the developmental goals you have identified for your child the basis for the provision and coordination of services and supports for your child?	❑	❑

5. FAMILIES ATTAIN THEIR GOALS

VALUES

Services and supports are organized and coordinated in a manner which assists families to attain their goals.

Service coordination and provision encourages families to be independent and self-sufficient.

QUESTIONS ABOUT QUALITY:	YES	NO
Has your family accomplished any goals since you began receiving services?	❑	❑
Have staff asked you what assistance or support you might need to attain your family goals?	❑	❑
Have you attained your goals within the time frames you had designated?	❑	❑

6. Children Attain Developmental Milestones

Values

Achieving developmental milestones at an early age provides children with foundational competencies that can be used throughout their lives.

When children attain important milestones, they and their families develop a sense of accomplishment and hope about the future.

Supports and training are provided to target skills and learning experiences that will facilitate children's attainment of important developmental milestones.

Children interact with same-aged peers in a variety of environments in which young children typically participate.

Questions About Quality:	YES	NO
Has your child learned any developmental skills since you began receiving services?	❑	❑
Are you satisfied with your child's progress?	❑	❑
Are you satisfied that everything possible has been done to enhance your child's development?	❑	❑

7. Families exercise their rights

Values

Families have information and other assistance to support them in actively exercising their rights.

Families are provided due process when they have a complaint or grievance.

Families advocate for their children and for themselves.

Questions About Quality:	YES	NO
Do you know what rights you have?	❑	❑
Do you know how you could exercise these rights?	❑	❑
Has anyone informed you of your rights?	❑	❑
Are your rights supported?	❑	❑
Have staff informed you of an appeals process or grievance procedure available to you if you have a complaint?	❑	❑
Has anyone told you about parent groups or other organizations that address self-advocacy issues for families of children with developmental concerns?	❑	❑

8. Children are free from abuse and neglect

Values

Children have physical and psychological freedom from all forms of abuse and neglect.

All allegations of abuse and neglect are addressed.

Questions About Quality:	YES	NO
Do you have any complaints about how your child has been treated by anyone affiliated with the program?	❑	❑
If so, do you know to whom concerns should be reported?	❑	❑
If you have had complaints, has anyone responded to these concerns?	❑	❑

9. Families are respected

Values

Children with developmental delays and disabilities are spoken of as children first.

The behavior of staff reflects sensitivity to the needs of families for privacy and dignity.

Confidentiality and normal sensibility are exercised when speaking about people.

The diversity of family experience is respected in all manners of interaction with families.

Questions About Quality:	YES	NO
Do you feel that staff respect you?	❑	❑
Do they treat your child in a respectful manner?	❑	❑
Do they respect your family situation?	❑	❑
Do staff listen to your comments and concerns?	❑	❑
Do they ask you for your opinion and input?	❑	❑
Do they seem to value your input?	❑	❑
Do all staff interactions and service practices reflect concern for your family's opinions, feelings and preferences?	❑	❑

10. Families decide when to share personal information

Values

All information known about the family is confidential.

Only information necessary to provide supports and/or services is requested of the family.

Information in the record is the property of the family.

Access to information about the family is limited to staff who need to know and to others specifically authorized by the family.

Questions About Quality:	YES	NO
Is your permission requested before information about your family/child is shared with anyone else?	❑	❑
Are you fully informed about what information is released and to whom?	❑	❑
Do staff ask you if there is any information you would not want shared?	❑	❑
Can you access your family's/child's record when you want to?	❑	❑
Do you know what information is kept in your family's/child's record?	❑	❑

11. CHILDREN HAVE THE BEST POSSIBLE HEALTH

VALUES

Families access health services for their children.

Best possible health is individually defined, given the unique characteristics of each child.

The definition of best possible health is important to directing and selecting health services.

QUESTIONS ABOUT QUALITY:	YES	NO
Does your child see a physician or other health care professional for regular check-ups?	❑	❑
Have staff asked you if you need any medical information?	❑	❑
Have staff asked you if your child needs any medical services?	❑	❑
Do staff ask you if you need support in carrying out any aspects of your child's health care?	❑	❑
Are your child's health care treatments/interventions working?	❑	❑
Have health care professionals identified your child's best possible health situation, addressing any health care issues or concerns and interventions?	❑	❑

12. CHILDREN ARE SAFE

VALUES

Children spend their time in environments that are safe.

Supports and information assist families in maintaining and selecting safe environments and situations for their children.

QUESTIONS ABOUT QUALITY:	YES	NO
Have staff asked you if there are any safety risks you are concerned about for your child?	❑	❑
Do you feel safe where you live? Is your child safe where you live?	❑	❑
Do staff ask you about safety concerns?	❑	❑
Do staff provide you with information about safety (such as information about car seats, cribs, CPR, First Aid training, stairway gates, outlet covers and special equipment)?	❑	❑
Does your family know how to respond in the event of an emergency?	❑	❑
If your child receives services in a center or community-based program, does it appear to be clean and safe?	❑	❑

13. FAMILIES REMAIN TOGETHER

VALUES

Families receive support to ensure that their children can be raised within the natural family home.

Families receive the support they need to ensure that they remain together.

QUESTIONS ABOUT QUALITY:	YES	NO
Have staff asked you about stresses associated with raising a child with a developmental delay/disability?	❑	❑
If you are a single parent, do staff ask you about additional supports you might need?	❑	❑
If your family is having difficulty dealing with the stresses of raising a child with a developmental delay/disability, have staff offered any support or told you about additional resources?	❑	❑
If your family is not together, have staff asked if there is anything early intervention can do to help reunite your family (if it is your desire to reunite)?	❑	❑

14. CHILDREN SPEND TIME IN NATURAL ENVIRONMENTS

VALUES

Children with disabilities/developmental delays have the right to access the same environments as any other children.

Children with and without developmental delays/disabilities can learn important things from one another.

Interactions with children without disabilities during the early years are linked to the child's ability to interact in adulthood.

QUESTIONS ABOUT QUALITY:	YES	NO
Does your child spend time with children who do not have developmental delays or disabilities?	❑	❑
Are you satisfied with the extent of time your child spends with children her/his own age who do not have disabilities/delays?	❑	❑
If you are not satisfied, have staff asked you if you need additional supports or resources to increase your child's experiences with other children?	❑	❑
Are typical environments such as preschools, day care centers and play groups available to your child?	❑	❑

15. CHILDREN DEVELOP RELATIONSHIPS

VALUES

Relationships provide lifelong supports for children.

The establishment of social relationships is an essential part of life for children.

The organization assists children in developing socialization skills and optimizes children's opportunities to form friendships and other relationships.

QUESTIONS ABOUT QUALITY:	YES	NO
Is your child forming relationships with others?	❑	❑
Is your child developing skills that enable her/him to interact with others?	❑	❑
Are you satisfied with the number of relationships your child is forming?	❑	❑
If not, is anything being done to enhance the development of relationships for your child?	❑	❑

16. FAMILIES REMAIN CONNECTED TO NATURAL SUPPORTS

VALUES

Natural support networks provide lifelong support and a safety net for families.

Families access supports that enable them to maintain connections to their natural supports according to their choices and preferences.

QUESTIONS ABOUT QUALITY:	YES	NO
Do you receive any help or support from family, friends or neighbors?	❑	❑
Do staff ever ask you about the extent of your natural supports?	❑	❑
Do staff ask you if you need help with any relationships or need additional supports?	❑	❑
Do staff ask you if you need some assistance expanding your natural support network?	❑	❑
Do staff ever ask you if you need help in maintaining or expanding your natural support network?	❑	❑

17. FAMILIES ARE A PART OF THEIR COMMUNITIES

VALUES

Families decide the type and extent of their own participation in community life.

Variance in the type and extent of community participation through activities and roles is based on family choice and preference.

Families may need support to assume roles in the community or be involved in community activities.

QUESTIONS ABOUT QUALITY:	YES	NO
Are you satisfied with your level of involvement in community functions or activities?	❑	❑
If not, have staff asked you if you need any supports to become more involved in the community?	❑	❑
Do you know what community activities, groups and leadership roles are available in you community?	❑	❑
Do staff ever ask you if you are satisfied with your level of participation in the community?	❑	❑

18. FAMILIES HAVE ECONOMIC RESOURCES

VALUES

Families have the resources to cover their basic needs.
Economic security enables families to plan their futures.

QUESTIONS ABOUT QUALITY:	YES	NO
Do you feel you have enough information about economic resources?	❑	❑
Do you have sufficient resources to pay your basic living expenses?	❑	❑
Have staff asked you if you need assistance in securing additional resources?	❑	❑
Have staff asked you if you need help securing ways to pay for costs related to your child's care, equipment or other supports?	❑	❑
Have staff asked you if you need information about your eligibility for various programs such as respite care, in-home family supports and medical assistance?	❑	❑
Have staff asked you if you need any help with budgeting or financial management?	❑	❑
Have staff inquired about your need for insurance or information about insurance?	❑	❑
Do staff ever ask you about family economic issues?	❑	❑

19. Families experience continuity and security

Values

Planning for major transitions minimizes the disruptive effects of these changes on family life.

Supports and services are provided with minimal disruption to a family's life.

When unplanned changes occur, the organization has a plan to address the effects on family life.

Systems advocacy promotes greater continuity and security in services for families.

Questions About Quality:	YES	NO
Do staff ask you if you have any anxieties or worries about your child's/family's future?	❑	❑
Do you feel you have control over your life?	❑	❑
Have you been told about staff changes in advance?	❑	❑
Has anything been done to minimize the disruption staff changes might have on your life/your child's life?	❑	❑
Has sufficient planning been done to help ease the anxiety related to transitions, particularly your child's transition to another program or service such as preschool?	❑	❑

20. Families are satisfied with their services

Values

Satisfaction is a critical aspect of service quality. The most important perspective on quality is the consumer's point of view.

The absence of a complaint does not mean the presence of satisfaction.

Organizations anticipate the need to modify service practices as children and families grow and change.

Questions About Quality:	YES	NO
Are you satisfied with your early intervention services?	❑	❑
If not, do you know with whom to voice your dissatisfaction?	❑	❑
Are you asked what you think about services?	❑	❑
If you have expressed any dissatisfaction, has anything been done about the situation?	❑	❑

21. FAMILIES ARE SATISFIED WITH THEIR LIFE SITUATIONS

VALUES

Family life satisfaction increases with the presence of natural support networks.

Satisfaction increases when families are able to select their own goals, direct their own services and exercise other types of control over their life situations.

QUESTIONS ABOUT QUALITY:	YES	NO
Are you happy with your overall personal life situation?	❑	❑
Has involvement with the program improved your personal life at all?	❑	❑
Do staff ever ask you if you are happy with your life situation?	❑	❑
If you are unhappy with your situation, have staff asked if there is anything they could do to help you improve your satisfaction with your life situation?	❑	❑